Empowerment: A Patient’s Perspective

I was diagnosed with type 1 diabetes in 1984. Since then, the improvements in the treatment of diabetes have been massive. I have gone from taking a daily injection of NPH insulin to continuous insulin infusion from an insulin pump. I now monitor my blood glucose level six or more times each day with relative precision rather than having to face the challenge of interpreting the color of urine test strips.

There were no certified diabetes educators in the office of my first endocrinologist’s practice. When I was hospitalized initially, the physician cautioned me to “humor” the visiting dietitian, and my family was excluded from my diabetes education. I was told that diabetes could be managed easily and that I could live a normal life with it.

When I began to face the many challenges of living with diabetes, I soon became frustrated and angry that control of my diabetes was not as easily attained as I was led to believe. Moreover, I thought this was the result of personal failing and that my feelings and experiences were unique to me.

Today, in contrast, my diabetes management team consists of an endocrinologist, several nurses who are certified diabetes educators, a dietitian, a podiatrist, a cardiologist, and an ophthalmologist. Psychosocial issues connected to diabetes, as recently validated by the Diabetes Attitudes, Wishes, and Needs (DAWN) program, are now recognized as a normal and important part of diabetes care. Education programs are more widely available and accessible. Things have certainly changed.

Assuredly, the past 20 years have been filled with many scientific and technological developments in the field of diabetes. In many respects, it truly has been an age of enlightenment and advances. From my perspective, however, the most significant innovation in diabetes management introduced during the past 2 decades has not been a product of either science or technology. Instead, it is based on an unprecedented study and understanding of patients’ behavior with an emphasis on psychosocial concerns.

Since its landmark (and in some quarters controversial) introduction in 1991, the empowerment approach to diabetes education and treatment has been embraced by diabetes educators and other health care professionals around the world, casting patients as the central figures in the design and implementation of their individual diabetes treatment plans. My initial diabetes management experience was largely a prescriptive exercise through which I was directed to follow regimens specified by an endocrinologist. I obtained informa-
tion by personally reading through largely didactic educational materials instructing me to follow an exchange-based meal plan and to adjust my life to fit the diabetes care recommendations of my doctor. The empowerment approach recognized that this method was likely to fail and that changes in patient behavior, which are so integral to the effective treatment of diabetes, could only be achieved when patients understand and select those changes for themselves. Seldom, if ever, can change be accomplished by health care provider mandate.

Central to this approach is the acknowledgment that individuals will only pursue courses of conduct that they comprehend and choose to follow. The primary focus for health care professionals, therefore, has been to provide patients with sufficient information and options to make informed choices.

Since the advent of the team approach to diabetes care, patients are now able to draw on the experience and expertise of an array of health care professionals with diverse backgrounds rather than being forced to rely on a single source for information. This collaborative approach has enabled patients to devise diabetes management plans that are adapted to their personal lifestyle needs and objectives as well as to their personal wants and desires, while still addressing the fundamental treatment requirements of their diabetes.

Of course, science and technology have had a major effect on the treatment of diabetes during this period. In fact, scientific advances have been instrumental to the overall success of the empowerment method. As science has solved more of the physiological and biochemical mysteries surrounding diabetes, the workings of the human body, and its genetic structure, the base of information that patients need to know has expanded exponentially. This, in turn, has further supported the advisability of a team approach that can divide the information among different diabetes care providers who have the specialized expertise to handle particular aspects of this growing body of knowledge. Additionally, the internet has proven to be a significant factor in the dissemination of this information.

Science has also contributed dramatically through the development of newer designer insulins and other medications that provide greater alternative medical therapies from which patients can make informed choices to suit their lifestyle needs. Some of these medications and other medical advances have also ameliorated and in some instances helped to prevent many of the complications that can result from less successful efforts at disease management.

Empowerment has been further facilitated by the introduction of faster, more accurate, and more affordable blood glucose monitoring devices that provide readings on a real-time basis so that patients can make necessary adjustments on the run. And progress over a more prolonged period can now be measured through a simple hemoglobin A1c blood test.

Like most people with diabetes, I am grateful for these developments in that they have allowed me greater flexibility in the management of my diabetes. These advances have allowed me to manage my diabetes while also accommodating my hectic and demanding professional life, which involves late-night meetings and a heavy travel schedule.

None of this is to imply that patient-centered care was a complete foreign concept for health care professionals before the recognition of the empowerment approach to diabetes education and treatment. Patient needs and requirements have always been a foremost concern. The empowerment approach merely acknowledges the manner in which patients incorporate changes into their lives and emphasizes their role as fundamental members of the treatment team with the ultimate power to reject the suggestions and recommendations of the other team members.

This approach has enabled me to take a much more active role in my personal health. I am now in a much better position to celebrate my successes. And when I fail to hit a target, I am more likely to analyze the reasons for it and make adjustments, rather than to feel the sense of failure that once accompanied my inevitable misses.

Many patients and their health care providers recognized this reality long ago, and the empowerment approach merely provided a name for what these individuals already practiced and believed. Patients have been making decisions and choosing which recommendations to follow (sometimes with devastating consequences) for years. The acknowledgment and acceptance of patient empowerment by health care professionals has validated the reality that patients have always possessed this power over their diabetes care and has substituted it for the outmoded concept of patient “noncompliance” with physician-prescribed regimens.

Just as in other arenas, patients’ power to devise their own treatment is not without a corresponding cost. There are times when I wish I did not have to work so hard to manage my diabetes or make as many decisions as I do. I still get frustrated when my body does not respond as I had expected. Indeed, the exercise of power bestows a weighty responsibility and accountability. Patients need help to understand and accept that the consequences of the choices they make are their responsibility and not the responsibility of their health care providers. After all, the patients will be the ones to suffer the complications.

This is all the more reason that patients need to be advised fully of the potential ramifications of the choices they face. By educating patients about the rationale supporting the diabetes management advice they receive and presenting treatment options, the likelihood of rejection diminishes and the probability of successful outcomes increases. This approach has certainly worked for me, and it has also worked for many of the other people with diabetes whom I have encountered. Diabetes education needs to be accomplished in an informative, nonthreatening manner to ensure understanding while emphasizing patients’ role in the decision-making process and remaining cognizant of their psychosocial concerns and needs. Otherwise, diabetes treatment will revert to being prescriptive once again, with a corresponding return to all of the disappointing and uncertain results of the past.

Undoubtedly, patients are equipped with various levels of skills, abilities, and motivation to accept the responsibility for designing and implementing their own diabetes management plans. But in only a very few situations are patients likely to possess none of the these characteristics. It is important for diabetes health care professionals to be on alert when speaking with their patients to identify and help them recognize and nurture the traits they do have that can help them stay involved...
in the diabetes management process. Similarly, different patients will relate differently to individual members of their diabetes care team. It is important that the professionals remain mindful of their respective abilities to engage particular patients and divide their assignments accordingly. This highly individualized approach may increase initial work requirements, but more successful outcomes will be sure to follow.

I was fortunate over the years to be a voracious reader who was able to learn much about diabetes through books and other publications. My “home schooling” was fortified by my associations with some of the nation’s leading diabetes professionals as I became more involved at the national level as a volunteer with the American Diabetes Association. Nevertheless, by virtue of these new methods, I now better understand my own diabetes and its effects on me. Had the empowerment approach, with its corresponding increased level of diabetes education and psychosocial support, been recognized and accepted at the time of my diagnosis, I may have been able to take control of my diabetes sooner and avoid some of the serious complications that I have experienced.

References


Michael A. Weiss has authored numerous articles and spoken publicly about diabetes from the patient’s perspective. He served as 2002–2003 chair of the American Diabetes Association.